

Marie Curie Research Grants Scheme

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Caregiver Experience of Conservatively Managed End-stage Kidney Disease: Informing the Development of a Psychosocial Intervention.

Abstract

Background - Chronic kidney disease presents a global health challenge in the context of an aging population. When chronic kidney disease progresses to end-stage kidney disease, treatment choices include dialysis and transplantation, often inappropriate for frail, elderly patients with additional co-morbidities. Dialysis treatment itself is often associated with a deterioration in functional status. An alternative option is conservative management, aimed at alleviating symptoms and psychosocial concerns and provided by the hospital healthcare and community teams until the death of the patient. Conservative management includes an attempt to slow the rate of renal disease progression and encourages end-of-life care planning. Patients managed conservatively rely heavily on informal carers, such as family or friends, to cope with debilitating, chronic kidney disease. These carers may experience a negative impact on their own quality of life exacting a toll on their physical, social and emotional wellbeing, and have significant unmet needs including physical and psychological impacts, financial disadvantage and social isolation. These carers are likely to experience substantial challenges as they take on multifaceted, often unfamiliar roles to support patients who can experience anguish and prognostic uncertainty. The adverse effects on caregiver physical and psychological health, including increased rates of depression and anxiety in end-stage kidney disease are documented in the literature. Caregiver strain has also been shown to adversely impact care recipient experience, as well as the sustainability of homecare. The needs of carers, supporting patients managed conservatively, have been neglected. Their experience is poorly reported and there are no current supportive interventions available to assist and support them in their care-giving role.

Aim - The aim of this study is to understand the experiences and unmet needs of carers of patients with end-stage kidney disease, managed conservatively, to inform, for the first time, the design of a psychosocial intervention to support them in their caring role.

Methods – The Medical Research Council guidelines for developing complex interventions will underpin this study of three phases: Phase 1 – A systematic review of psychosocial interventions in chronic disease, and qualitative in-depth interviews with 60 informal carers across Northern Ireland and England; Phase 2 – focus groups with healthcare staff and carers to report back from interviews and identify key components for a psychosocial intervention; Phase 3 – feedback on a potential intervention through national workshops to engage the UK renal community. Findings from Phase 1 and 2 will be shared and small teams within the workshop will help to refine and confirm the acceptability of the proposed intervention. The interviews with carers will explore their perceptions of care provision, caregiving experiences as well as contextual factors influencing the design and delivery of a suitable psychosocial intervention. We will continue our work alongside healthcare staff, as well as patients and carers via an Expert Advisory Group and the Northern Ireland Kidney Patient Association, to co-design the intervention, and delivery methods to facilitate the intervention. Collaborators include Kidney Care UK, and the Northern Ireland Kidney Patient Association who will be represented on the Expert Advisory Group and at the workshops. We will also continue our relationships with other UK groups including the British Renal Society, the leading multi-professional renal organisation in the UK with a core aim of promoting effective multi professional care to improve quality of life for

people with kidney disease, their families, and carers.

Implications for practice – The study, aligned with key stakeholders and the Medical Research Council framework will inform the rigorous development of a novel psychosocial intervention aimed at improving the psychological wellbeing of carers, and enhance the experience of care giving to patients with end-stage kidney disease managed conservatively. The study and workshops are aimed at engaging healthcare and policy staff, patients, and carers across the UK, to encourage participation in a future definitive randomised controlled trial. This study constitutes the first stage of work aimed at building a rigorous evidence base for a psychosocial intervention in this renal carer population. Importantly it will increase equitable access for carers to an evidence-based tool and research that improves the lives of carers and patients and impacts positively on the renal community.